



NORD[®]

National Organization
for Rare Disorders

FINANCIAL STATEMENTS
DECEMBER 31, 2020 AND 2019

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

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December 31, 2020 and 2019

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Independent Auditor's Report

To the Board of Directors of
National Organization for Rare Disorders, Inc.:

Report on the Financial Statements

We have audited the accompanying financial statements of National Organization for Rare Disorders, Inc. (a New York corporation, not for profit) which comprise the statements of financial position as of December 31, 2020 and 2019, and the related statements of activities without donor restrictions, changes in net assets and cash flows for the years then ended, and the related notes to the financial statements.

Management's Responsibility for the Financial Statements

Management is responsible for the preparation and fair presentation of these financial statements in accordance with accounting principles generally accepted in the United States of America; this includes the design, implementation, and maintenance of internal control relevant to the preparation and fair presentation of financial statements that are free from material misstatement, whether due to fraud or error.

Auditor's Responsibility

Our responsibility is to express an opinion on these financial statements based on our audits. We conducted our audits in accordance with auditing standards generally accepted in the United States of America. Those standards require that we plan and perform the audits to obtain reasonable assurance about whether the financial statements are free from material misstatement.

An audit involves performing procedures to obtain audit evidence about the amounts and disclosures in the financial statements. The procedures selected depend on the auditor's judgment, including the assessment of the risks of material misstatement of the financial statements, whether due to fraud or error. In making those risk assessments, the auditor considers internal control relevant to the entity's preparation and fair presentation of the financial statements in order to design audit procedures that are appropriate in the circumstances, but not for the purpose of expressing an opinion on the effectiveness of the entity's internal control. Accordingly, we express no such opinion. An audit also includes evaluating the appropriateness of accounting policies used and the reasonableness of significant accounting estimates made by management, as well as evaluating the overall presentation of the financial statements.

We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our audit opinion.

Opinion

In our opinion, the financial statements referred to above present fairly, in all material respects, the financial position of National Organization for Rare Disorders, Inc. as of December 31, 2020 and 2019, and the changes in its net assets and its cash flows for the years then ended in accordance with accounting principles generally accepted in the United States of America.

AAFCPAs, Inc.

Westborough, Massachusetts
July 2, 2021

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Financial Position
December 31, 2020 and 2019

Assets	2020	2019
Current Assets:		
Cash and cash equivalents	\$ 23,512,112	\$ 47,832,054
Accounts receivable, net of allowance for doubtful accounts of \$200,000 and \$195,000 at December 31, 2020 and 2019, respectively	1,358,053	11,775,250
Prepaid expenses	368,116	229,136
Investments	25,613,110	-
Total current assets	50,851,391	59,836,440
Restricted Cash	200,000	-
Investments - Deferred Compensation	108,394	136,831
Deferred Hosting Arrangement Costs	109,919	189,191
Property, Equipment and Software, net	1,316,605	1,487,761
Software Under Development	188,231	100,873
Total assets	\$ 52,774,540	\$ 61,751,096
Liabilities and Net Assets		
Current Liabilities:		
Current portion of long-term debt	\$ 70,844	\$ 67,463
Accounts payable	587,335	660,712
Accrued expenses	662,999	260,474
Current portion of research grants payable	1,098,220	481,474
Deferred revenue	248,181	223,059
Total current liabilities	2,667,579	1,693,182
Deferred Compensation	108,394	136,831
Research Grants Payable, net of current portion	265,000	265,000
Long-Term Debt, net of current portion	165,915	236,760
Total liabilities	3,206,888	2,331,773
Net Assets:		
Without donor restrictions:		
Operating	5,877,691	3,830,508
Property, equipment and software and software under development	1,268,077	1,210,812
Total without donor restrictions	7,145,768	5,041,320
With donor restrictions	42,421,884	54,378,003
Total net assets	49,567,652	59,419,323
Total liabilities and net assets	\$ 52,774,540	\$ 61,751,096

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Activities Without Donor Restrictions
For the Years Ended December 31, 2020 and 2019

	<u>2020</u>	<u>2019</u>
Changes in Net Assets Without Donor Restrictions:		
Patient services:		
Program fees	\$ 345,353	\$ 639,674
Net assets released from purpose restrictions	39,755,627	30,173,232
Patient assistance and reimbursement expense	<u>(40,100,980)</u>	<u>(30,812,906)</u>
Patient services, net	<u>-</u>	<u>-</u>
Research grants:		
Net assets released from purpose restrictions	631,258	535,130
Research grant expense	<u>(631,258)</u>	<u>(535,130)</u>
Research grants, net	<u>-</u>	<u>-</u>
Other revenue and support:		
Grants, contributions and bequests	4,122,303	1,111,020
Special events revenue	1,900,601	2,405,019
Registry, web subscriptions and other related fees	395,674	234,128
Interest and dividend income, net	328,049	595,629
Drug, travel and lodging program administrative fees	67,425	174,162
Net assets released from purpose restrictions - patient service administrative fees	3,756,095	4,493,330
Net assets released from time restrictions - membership dues	1,783,062	1,680,303
Net assets released from purpose restrictions - contributions	1,755,460	1,775,409
Net assets released from purpose restrictions - research grant administrative fees	<u>52,000</u>	<u>34,020</u>
Total other revenue and support	<u>14,160,669</u>	<u>12,503,020</u>
Other operating expenses:		
Personnel and related	8,470,391	6,630,675
Professional fees	1,156,404	740,762
Other	562,754	376,844
Occupancy	521,385	538,733
Depreciation	486,500	545,820
Data systems and equipment	456,801	328,595
Conferences, meetings and travel	<u>401,986</u>	<u>1,589,511</u>
Total other operating expenses	<u>12,056,221</u>	<u>10,750,940</u>
Changes in net assets without donor restrictions	<u>\$ 2,104,448</u>	<u>\$ 1,752,080</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Changes in Net Assets
For the Years Ended December 31, 2020 and 2019

	Without Donor Restrictions	With Donor Restrictions					Total	
		Patient Service	Research Grants	Membership Dues	Endowment	Other		
Net Assets, December 31, 2018	<u>\$ 3,289,240</u>	<u>\$ 43,315,648</u>	<u>\$ 1,307,632</u>	<u>\$ 85,000</u>	<u>\$ -</u>	<u>\$ 798,120</u>	<u>\$ 45,506,400</u>	<u>\$ 48,795,640</u>
Revenue without donor restrictions	5,159,632	-	-	-	-	-	-	5,159,632
Grants and contributions with donor restrictions	-	43,657,500	576,127	1,665,303	-	1,664,097	47,563,027	47,563,027
Net assets released from donor restrictions	38,691,424	(34,666,562)	(569,150)	(1,680,303)	-	(1,775,409)	(38,691,424)	-
Transfers	-	242,307	-	-	-	(242,307)	-	-
Total expenses	<u>(42,098,976)</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(42,098,976)</u>
Changes in net assets	<u>1,752,080</u>	<u>9,233,245</u>	<u>6,977</u>	<u>(15,000)</u>	<u>-</u>	<u>(353,619)</u>	<u>8,871,603</u>	<u>10,623,683</u>
Net Assets, December 31, 2019	<u>5,041,320</u>	<u>52,548,893</u>	<u>1,314,609</u>	<u>70,000</u>	<u>-</u>	<u>444,501</u>	<u>54,378,003</u>	<u>59,419,323</u>
Revenue without donor restrictions	7,159,405	-	-	-	-	-	-	7,159,405
Grants and contributions with donor restrictions	-	28,765,208	195,537	2,180,562	200,000	4,436,076	35,777,383	35,777,383
Net assets released from donor restrictions	47,733,502	(43,511,722)	(683,258)	(1,783,062)	-	(1,755,460)	(47,733,502)	-
Transfers	-	115,744	-	-	-	(115,744)	-	-
Total expenses	<u>(52,788,459)</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>-</u>	<u>(52,788,459)</u>
Changes in net assets	<u>2,104,448</u>	<u>(14,630,770)</u>	<u>(487,721)</u>	<u>397,500</u>	<u>200,000</u>	<u>2,564,872</u>	<u>(11,956,119)</u>	<u>(9,851,671)</u>
Net Assets, December 31, 2020	<u>\$ 7,145,768</u>	<u>\$ 37,918,123</u>	<u>\$ 826,888</u>	<u>\$ 467,500</u>	<u>\$ 200,000</u>	<u>\$ 3,009,373</u>	<u>\$ 42,421,884</u>	<u>\$ 49,567,652</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Statements of Cash Flows

For the Years Ended December 31, 2020 and 2019

	<u>2020</u>	<u>2019</u>
Cash Flows from Operating Activities:		
Changes in net assets	\$ (9,851,671)	\$ 10,623,683
Adjustments to reconcile changes in net assets to net cash provided by operating activities:		
Depreciation	486,500	545,820
Bad debt	5,000	-
Amortization of hosting arrangement costs	79,272	71,965
Net gain on investments	(49,617)	-
Donated investments	4,948	118,421
Changes in operating assets and liabilities:		
Accounts receivable	10,412,197	(9,087,648)
Prepaid expenses	(138,980)	87,862
Deferred hosting arrangement costs	-	(154,093)
Accounts payable	222	185,845
Accrued expenses	402,525	66,604
Research grants payable	616,746	272,396
Deferred revenue	25,122	(277,593)
Deferred compensation	(28,437)	32,779
Net cash provided by operating activities	<u>1,963,827</u>	<u>2,486,041</u>
Cash Flows from Investing Activities:		
Proceeds from sales (purchase) of investments	1,090,282	(118,421)
Proceeds from sale (purchase) of investments - deferred compensation	28,437	(32,779)
Purchase of investments	(26,658,723)	-
Investment in software under development	(476,301)	(338,463)
Acquisition of property, equipment and software	-	(72,862)
Net cash used in investing activities	<u>(26,016,305)</u>	<u>(562,525)</u>
Cash Flows from Financing Activities:		
Principal payments on long-term debt	(67,464)	(64,245)
Net Change in Cash, Cash Equivalents and Restricted Cash	<u>(24,119,942)</u>	<u>1,859,271</u>
Cash, Cash Equivalents and Restricted Cash:		
Beginning of year	<u>47,832,054</u>	<u>45,972,783</u>
End of year	<u>\$ 23,712,112</u>	<u>\$ 47,832,054</u>
Reconciliation of Cash, Cash Equivalents and Restricted Cash Reported Within the Statements of Financial Position:		
Cash and cash equivalents	\$ 23,512,112	\$ 47,832,054
Restricted cash	<u>200,000</u>	<u>-</u>
Total cash, cash equivalents and restricted cash	<u>\$ 23,712,112</u>	<u>\$ 47,832,054</u>
Supplemental Disclosure of Cash Flow Information:		
Cash paid for interest	<u>\$ 13,405</u>	<u>\$ 16,625</u>
Supplemental Disclosure of Non-Cash Transactions:		
Software under development placed in service	<u>\$ 315,344</u>	<u>\$ 335,132</u>
Software in development in accounts payable	<u>\$ -</u>	<u>\$ 73,599</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2020 and 2019

1. OPERATIONS AND NONPROFIT STATUS

National Organization for Rare Disorders, Inc. (NORD) is a not-for-profit organization incorporated on May 4, 1983, under the laws of the State of New York.

NORD was formed to provide information on rare disorders and related resources, to aid government agencies in activities pursuant to the Orphan Drug Act, to encourage and promote increased scientific and clinical research on rare disorders, to support and mentor disease-specific patient organizations, and to provide services to patients and their families, especially to enhance their access to medical treatment for their diseases. NORD manages both indigent care drug programs that provide medication at no cost to those in need and financial hardship relief programs to provide individuals who meet objective criteria with insurance premium and co-payment assistance through funds raised by NORD from grants and donations from foundations, corporations and individuals.

NORD's main office is in Quincy, Massachusetts, with additional offices in Danbury, Connecticut and Washington, D.C.

NORD is exempt from Federal income taxes as an organization (not a private foundation) formed for charitable purposes under Section 501(c)(3) of the Internal Revenue Code (IRC). NORD is also exempt from state income taxes. Donors may deduct contributions made to NORD within the requirements of the IRC.

2. SIGNIFICANT ACCOUNTING POLICIES

NORD's financial statements have been prepared in accordance with accounting standards generally accepted in the United States of America (U.S. GAAP). References to U.S. GAAP in these notes are to the FASB Accounting Standards Codification (ASC).

Cash and Cash Equivalents

For the purpose of the statements of cash flows, management considers all highly liquid investments with an initial maturity of three months or less to be cash and cash equivalents. These funds include investments, overnight bank deposits, and other short-term highly liquid securities.

Restricted Cash

Restricted cash consists of cash restricted for the endowment (see Note 4) at December 31, 2020.

Accounts Receivable and Allowance for Doubtful Accounts

Accounts receivable at December 31, 2020 and 2019, include approximately \$1,023,000 and \$11,145,000, respectively, due in the next year for program grants. An allowance for doubtful accounts is based on collection experience and other circumstances which may affect the ability of NORD to collect. The allowance for doubtful accounts at December 31, 2020 and 2019, was \$200,000 and \$195,000, respectively. Accounts receivable also includes contract service receivables of approximately \$313,000 and \$631,000, respectively, representing unconditional rights to consideration and only the passage of time is required before the payment of that consideration is due. Any estimated uncollectible amounts are generally considered implicit price concessions which directly reduce accounts receivable. Changes to the estimate of the transaction price are generally recorded as adjustments to revenue in the period of the change. Subsequent changes that are determined to be the result of an adverse change in the payer's ability to pay are recorded as bad debt expense.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2020 and 2019

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Fair Value Measurements

NORD follows the accounting and disclosure standards pertaining to ASC Topic, *Fair Value Measurements*, for qualifying assets and liabilities. Fair value is defined as the price that NORD would receive upon selling an asset or pay to settle a liability in an orderly transaction between market participants.

NORD uses a framework for measuring fair value that includes a hierarchy that categorizes and prioritizes the sources used to measure and disclose fair value. This hierarchy is broken down into three levels based on inputs that market participants would use in valuing the financial instruments based on market data obtained from sources independent of NORD. Inputs refer broadly to the assumptions that market participants would use in pricing the financial instrument, including assumptions about risk. Inputs may be observable or unobservable. Observable inputs are inputs that reflect the assumptions market participants would use in pricing the financial instrument developed based on market data obtained from sources independent of the reporting entity. Unobservable inputs are inputs that reflect the reporting entity's own assumptions about the assumptions market participants would use in pricing the asset developed based on the best information available.

The three-tier hierarchy of inputs is summarized in the three broad levels as follows:

Level 1 - Inputs that reflect unadjusted quoted prices in active markets for identical assets at the measurement date.

Level 2 - Inputs other than quoted prices that are observable for the asset either directly or indirectly, including inputs in markets that are not considered to be active.

Level 3 - Inputs that are unobservable and which require significant judgment or estimation.

An asset or liability's level within the framework is based upon the lowest level of any input that is significant to the fair value measurement. All assets are valued using Level 1 inputs except as noted in Note 5.

Deferred Hosting Arrangement Costs and Amortization

Implementation costs, including set up and other upfront fees, that are incurred to implement a hosting arrangement service contract are capitalized. Deferred hosting arrangement costs are expensed over the term of the hosting arrangements, including any reasonably certain renewal periods. Deferred hosting arrangement costs as of December 31, 2020 and 2019, include unamortized implementation costs related to NORD's budgeting and reporting software and development software. The deferred hosting arrangement costs are expected to be amortized through March 2022. Amortization expense was \$79,272 and \$71,965 for the years ended December 31, 2020 and 2019, respectively, and is included in data systems and equipment in the accompanying statements of activities without donor restrictions.

Software Under Development

Software under development includes the cost to advance and update NORD's proprietary software. The cost related to software or modules not placed in service as of December 31, 2020 and 2019, was \$188,231 and \$100,873, respectively, and is reflected as software under development in the accompanying statements of financial position. When the software update or advance is implemented, it is placed in service, depreciated, and the asset is transferred to property, equipment and software in the accompanying statements of financial position.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2020 and 2019

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Marketing and Advertising Costs

NORD expenses marketing and advertising costs as they are incurred.

Research Grants Payable

Research grants are recorded when awarded by NORD. Payments are made when certain milestones are met by the researchers. The final payment is made when the research is considered substantially completed. Research grants expected to be paid during the subsequent fiscal year are shown as current liabilities in the accompanying statements of financial position. Non-current research grants payable are expected to be paid in 2022 or beyond.

Property, Equipment and Software and Depreciation

Property, equipment and software are recorded at cost when purchased or developed or at fair value at the time of donation. Renewals and betterments are capitalized, while repairs and maintenance are expensed as they are incurred.

Depreciation is computed using the straight-line method over the following estimated useful lives:

	<u>Estimated Useful Lives</u>
Building and improvements	5 - 20 years
Furniture and fixtures	5 - 10 years
Computers and computer software	3 - 5 years

Land is not depreciated.

NORD accounts for the carrying value of its property and equipment in accordance with the requirements of *Impairment and Disposal of Long-Lived Assets*. As of December 31, 2020 and 2019, NORD has not recognized any reduction in the carrying value of its property and equipment in consideration of the requirement.

Net Assets

Net Assets Without Donor Restrictions

Net assets without donor restrictions are those net resources that bear no external restrictions and are generally available for use by NORD. NORD has grouped its net assets without donor restrictions into the following categories:

Operating - Represents resources available to carry on the operations of NORD.

Property, equipment and software and software under development - Represents the activities relating to NORD's property, equipment and software and software under development, net of related debt, if any.

Net Assets With Donor Restrictions

Net assets with donor restrictions represent amounts received or committed with donor restrictions that have not yet been expended for their designated purpose (purpose restricted) or amounts for use in future periods (time restricted).

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2020 and 2019

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Net Assets (Continued)

Net Assets With Donor Restrictions (Continued)

Net assets with donor restrictions also include endowment funds which are perpetual in nature (see Note 4). Earnings from this fund may be used for operations unless otherwise stipulated by the donor. In accordance with Massachusetts law, all earnings, including interest and dividends, and appreciation of a donor-restricted endowment are restricted until appropriated by the Board of Directors, and are released to net assets without donor restrictions based on NORD's spending policy.

As of December 31, 2020 and 2019, net assets with donor restrictions are restricted for the following:

	<u>2020</u>	<u>2019</u>
Purpose restricted	\$ 41,438,384	\$ 53,125,003
Time restricted	783,500	1,253,000
Perpetual in nature	<u>200,000</u>	<u>-</u>
Total	<u>\$ 42,421,884</u>	<u>\$ 54,378,003</u>

Revenue Recognition

In accordance with Accounting Standards Update (ASU) No. 2018-08, *Not-for-Profit Entities (Topic 958): Clarifying the Scope and the Accounting Guidance for Contributions Received and Contributions Made*, NORD must determine whether a contribution (or a promise) is conditional or unconditional for transactions deemed to be a contribution. A contribution is considered to be a conditional contribution if an agreement includes a barrier that must be overcome and either a right of return of the assets or a right of release of a promise to transfer assets exists. Indicators of a barrier include a measurable performance-related barrier or another measurable barrier, a stipulation that limits discretion by the recipient on the conduct of an activity, and stipulations that are related to the purpose of the agreement. Topic 958 prescribes that NORD should not consider probability of compliance with the barrier when determining if such awards are conditional and should be reported as conditional grant advance liabilities until such conditions are met. At December 31, 2020, NORD had conditional promises to give subject to matching and measurable performance barriers of \$1,257,656. These conditions are expected to be satisfied in 2021, at which time they will be recognized as revenue. NORD had no conditional grants at December 31, 2019.

NORD reports gifts and grants of cash and other assets as revenue and net assets with donor restrictions if they are received or unconditionally committed with donor stipulations that limit the use of the asset. When a donor restriction expires, that is, when a stipulated time restriction ends or purpose restriction is accomplished, net assets with donor restrictions are reclassified to net assets without donor restrictions and reported in the statement of activities without donor restrictions as net assets released from restrictions. Revenue from grants and contributions without donor restrictions is recorded when received or unconditionally committed by the donor.

Patient service program and administration fees are recorded as net assets with donor restrictions. When expense criteria are met, patient service program and administration fee revenue is recorded as net assets released from purpose restrictions under patient services in the statement of activities without donor restrictions.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2020 and 2019

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Revenue Recognition (Continued)

Research grant contributions are received and held as donor restricted contributions until a research grant award is given and are reclassified as net assets released from restrictions in the statement of activities without donor restrictions. Research grants administration fee revenue is withheld from the grant award and released from restriction upon award date. The research grants administration fee revenue is considered peripheral to the research grant award transaction and are not considered an exchange transaction as no direct benefit is received by the research grant funder.

Sponsorships, included in registry, web subscriptions and other related fees in the statement of activities without donor restrictions, are recorded upon receipt and are recorded as net assets with donor restrictions. When expense criteria are met, revenue is recorded as net assets released from restrictions - contributions in the statement of activities without donor restrictions.

Membership dues, which are non-refundable, represent contributions restricted to the time period representing the membership period. The value of any membership services provided in exchange for membership rights are considered peripheral to the transaction. Membership dues are recorded as net assets with donor restrictions based upon the implied time restriction related to the effective membership period. Membership dues are reclassified to net assets without donor restrictions over time as time restrictions lapse and are reported in the statement of activities without donor restrictions as net assets released from time restrictions - membership dues.

NORD is and may be named beneficiary of trusts and wills. The amounts to be received, if any, cannot always be determined and are therefore not reflected in the accompanying financial statements because the donors' wills have not yet been declared valid by the probate court, and the value of the amounts to be received is not yet determinable. Bequests are recorded at a point in time when received. NORD received bequests of \$684,606 and \$5,723 for the years ended December 31, 2020 and 2019, respectively, which are included in grants, contributions and bequests in the accompanying statements of activities without donor restrictions.

NORD evaluates its revenue contracts with customers based on the five-step model under FASB's ASU No. 2014-09, *Revenue from Contracts with Customers (Topic 606)*: (1) Identify the contract with the customer; (2) Identify the performance obligations in the contract; (3) Determine the transaction price; (4) Allocate the transaction price to separate performance obligations; and (5) Recognize revenue when (or as) each performance obligation is satisfied.

Drug, travel and lodging program fees, patient services program fees and registry, web subscriptions and other related fees represent service revenue earned under contractual agreements with customers and is recorded over time as services are provided. Revenue is reported at the stated contract price with adjustments for any consideration for explicit and implicit price considerations. Advance payments on these fees are recorded as deferred revenue until contract obligations are met at which point they are recognized as revenue.

All other revenue is recorded when earned.

Income Taxes

NORD accounts for uncertainty in income taxes in accordance with ASC Topic, *Income Taxes*. This standard clarifies the accounting for uncertainty in tax positions and prescribes a recognition threshold and measurement attribute for the financial statements regarding a tax position taken or expected to be taken in a tax return. NORD has determined that there are no uncertain tax positions which qualify for either recognition or disclosure in the financial statements at December 31, 2020 and 2019. NORD's information returns are subject to examination by the Federal and state jurisdictions.

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2020 and 2019

2. SIGNIFICANT ACCOUNTING POLICIES (Continued)

Estimates

The preparation of financial statements in accordance with U.S. GAAP requires management to make estimates and assumptions that affect the reported amounts of assets and liabilities and disclosure of contingent assets and liabilities at the date of the financial statements and the reported amounts of revenues and expenses during the reporting period. Actual results could differ from those estimates.

Expense Allocation

Certain expenses are incurred which support the work performed under more than one grant or contract. Such expenses are allocated among the various grants and contracts based upon management's calculation of the amount attributable to each grant or contract. Expenses incurred for specific grants or contracts are charged directly to the applicable project.

The financial statements contain certain categories of expenses that are attributable to program and supporting functions and are allocated on a reasonable basis that is consistently applied. The expenses that are allocated include occupancy and depreciation, which are allocated based on estimates of square footage occupied, as well as personnel and related, which are allocated based on an estimation of time spent, head count and level of effort spent on NORD's program and supporting functions.

Subsequent Events

Subsequent events have been evaluated through July 2, 2021, which is the date the financial statements were available to be issued. Except as disclosed in Note 14, there were no events that met the criteria for recognition or disclosure in the financial statements.

3. FUNCTIONAL EXPENSES

Expense allocation by function and classification is as follows for the years ended December 31:

	2020			Total
	Programs	General and Adminis- trative	Supporting Services Development and Communication	
Patient assistance and reimbursement	\$ 40,100,980	\$ -	\$ -	\$ 40,100,980
Personnel and related	5,208,063	1,997,023	1,265,305	8,470,391
Professional fees	763,263	167,636	225,505	1,156,404
Research grant expense	631,258	-	-	631,258
Other	322,869	131,658	108,227	562,754
Occupancy	217,275	245,066	59,044	521,385
Depreciation	451,727	19,263	15,510	486,500
Data systems and equipment	119,530	227,441	109,830	456,801
Conferences, meetings and travel	323,148	19,749	59,089	401,986
Total	<u>\$ 48,138,113</u>	<u>\$ 2,807,836</u>	<u>\$ 1,842,510</u>	<u>\$ 52,788,459</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
December 31, 2020 and 2019

3. FUNCTIONAL EXPENSES (Continued)

	2019			Total
	Programs	Supporting Services		
		General and Adminis- trative	Development and Communication	
Patient assistance and reimbursement	\$ 30,812,906	\$ -	\$ -	\$ 30,812,906
Personnel and related	3,441,946	2,135,039	1,053,690	6,630,675
Professional fees	437,613	242,471	60,678	740,762
Research grant expense	535,130	-	-	535,130
Other	235,162	50,206	91,476	376,844
Occupancy	284,649	175,268	80,816	538,733
Depreciation	509,778	21,811	14,231	545,820
Data systems and equipment	81,781	163,025	83,789	328,595
Conferences, meetings and travel	<u>1,122,833</u>	<u>142,277</u>	<u>324,401</u>	<u>1,589,511</u>
Total	<u>\$ 37,461,798</u>	<u>\$ 2,928,097</u>	<u>\$ 1,709,081</u>	<u>\$ 42,098,976</u>

4. ENDOWMENT

During 2020, NORD received a \$200,000 endowment restricted in perpetuity. NORD follows the Massachusetts Uniform Prudent Management of Institutional Funds Act (UPMIFA). NORD developed a formal endowment spending policy whereas the corpus shall not be used to pay current expenses, other than investment service fees. The corpus shall be invested and returns may be used by NORD on an annual basis, starting three years after the funds are invested. The annual spending will be calculated as the greater of zero or half of the average annual return over the prior three years, calculated from the calendar year-end balance. NORD may decide, at its discretion, to delay or forego the annual withdrawal from the portfolio. NORD will not spend endowed funds from the endowment until after March 2024, three years after the initial investment. There were no amounts appropriated for spending from endowment funds during 2020 and no unspent appreciation of endowment funds as of December 31, 2020.

5. INVESTMENTS

At December 31, 2019 and 2020, investments, summarized using the inputs under the ASC Topic, *Fair Value Measurements* standard, consist of the following:

Description	2020			Total
	Level 1	Level 2	Level 3	
Corporate bonds	\$ -	\$ 19,035,585	\$ -	\$ 19,035,585
Asset backed securities	-	5,686,874	-	5,686,874
US Treasury bills	-	890,651	-	890,651
Total investments	<u>\$ -</u>	<u>\$ 25,613,110</u>	<u>\$ -</u>	<u>\$ 25,613,110</u>
Investments - Deferred Compensation (see Note 9)				
Mutual Fund	<u>\$ 108,394</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 108,394</u>

NATIONAL ORGANIZATION FOR RARE DISORDERS, INC.

Notes to Financial Statements
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5. INVESTMENTS (Continued)

<u>Description</u>	<u>2019</u>			<u>Total</u>
	<u>Level 1</u>	<u>Level 2</u>	<u>Level 3</u>	
Investments - Deferred Compensation (see Note 9) Mutual Fund	<u>\$ 136,831</u>	<u>\$ -</u>	<u>\$ -</u>	<u>\$ 136,831</u>

Investment return consists of the following for the year ended December 31, 2020:

	<u>2020</u>
Interest and dividends	\$ 238,857
Unrealized gains	17,088
Investment management fees	(38,660)
Realized losses	<u>(167,668)</u>
	<u>\$ 49,617</u>

Investment return is included in interest and dividend income, net in the accompanying statement of activities without donor restrictions at December 31, 2020.

6. PROPERTY, EQUIPMENT AND SOFTWARE

Net property, equipment and software consisted of the following as of December 31:

	<u>2020</u>	<u>2019</u>
Land	\$ 505,203	\$ 505,203
Building and improvements	857,182	857,182
Computers and computer software	3,181,529	2,866,185
Furniture and fixtures	<u>31,731</u>	<u>31,731</u>
	4,575,645	4,260,301
Less - accumulated depreciation	<u>3,259,040</u>	<u>2,772,540</u>
Net property, equipment and software	<u>\$ 1,316,605</u>	<u>\$ 1,487,761</u>

7. LONG-TERM DEBT AND LINE OF CREDIT

NORD has a mortgage note payable to a bank that is secured by certain property. Payments of principal and interest at 4.9% are due in monthly installments of \$6,739 through February 2024, the note's maturity. Subsequent to year-end, the interest rate was adjusted from 4.9% to 3.5% effective March 27, 2021 (see Note 14). Interest paid on the note was \$13,405 and \$16,625 for the years ended December 31, 2020 and 2019, respectively, which is included in other in the accompanying statements of activities without donor restrictions. The balance outstanding on the note was \$236,759 and \$304,223 as of December 31, 2020 and 2019, respectively.

The note agreement contains various covenants with which NORD must comply. At December 31, 2020 and 2019, NORD was in compliance with the covenants.

The future principal payments are as follows:

2021	\$ 70,844
2022	\$ 74,395
2023	\$ 78,123
2024	\$ 13,397

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Notes to Financial Statements
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7. LONG-TERM DEBT AND LINE OF CREDIT (Continued)

NORD has a line of credit with a bank which allows for borrowings up to \$750,000 and is renewable annually by the bank. The line of credit through May 31, 2021, was extended subsequent to year-end through July 30, 2021 (see Note 14). Borrowings under the agreement are due no later than the expiration date and interest is payable monthly at the London Interbank Offered Rate (LIBOR) Daily Floating Rate plus 2.5%. The line of credit is secured by NORD's property. No amounts were drawn on the line of credit during 2020 or 2019.

8. LEASE AGREEMENTS

NORD leases office space under operating leases in Massachusetts and Washington D.C., which expire in June 2022 and April 2024, respectively. Monthly payments under the terms of the agreements were \$6,614 during 2020 and 2019. In future years, payments range from \$6,614 to \$10,440. The facility leases require NORD to maintain certain insurance coverage and pay for its proportionate share of real estate taxes and operating expenses, as defined in the agreements. Rent expense was \$258,868 and \$255,691 for the years ended December 31, 2020 and 2019, respectively, which is included in occupancy in the accompanying statements of activities without donor restrictions. One of the facility leases is recorded on the straight-line method over the lease term. The rent accrued in excess of the rent paid, approximately \$19,000 and \$26,000, is included in accrued expenses in the accompanying statements of financial position as of December 31, 2020 and 2019, respectively.

Future minimum base lease payments under these agreements are as follows:

2021	\$ 199,248
2022	\$ 140,928
2023	\$ 79,368
2024	\$ 26,456

Both lease agreements contain renewal options.

9. EMPLOYMENT BENEFIT PLANS

NORD maintains a tax-deferred pension plan under Section 403(b) of the IRC. Employees may contribute to the plan, however, employer contributions are not allowable under the plan.

NORD also maintained a defined contribution pension plan under Section 401(a) of the IRC. NORD contributed 5% of each participant's annual salary into the plan. In 2020, the 401(a) plan was terminated and participants were given the option to receive a pay out of the funds or transfer the funds into the 403(b) plan. NORD's contributions for the years ended December 31, 2020 and 2019, totaled \$297,849 and \$250,201, respectively, which are included in personnel and related in the accompanying statements of activities without donor restrictions.

NORD maintains deferred compensation plans for certain members of its senior management team. NORD makes annual discretionary contributions to these plans as determined by the Board of Directors. The total amounts accrued for these plans as of December 31, 2020 and 2019, are \$108,394 and \$136,831, respectively, which are included in investment - deferred compensation and deferred compensation in the accompanying statements of financial position. The liability is classified as long-term since NORD intends to pay the balances to certain retired employees in accordance with the plans. These employees will receive payments upon retirement, which is expected to be more than one year from the statements of financial position date. NORD's contribution expense under the plans was \$47,154 and \$32,779 for the years ended December 31, 2020 and 2019, respectively, which is included in personnel and related in the accompanying statements of activities without donor restrictions.

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Notes to Financial Statements
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10. CONCENTRATIONS

NORD maintains its operating cash balances in various banks. The Federal Deposit Insurance Corporation (FDIC) insures balances at each bank up to certain amounts. At certain times during the years ended December 31, 2020 and 2019, cash balances exceeded the insured amounts. NORD has not experienced any losses in such accounts. NORD believes it is not exposed to any significant credit risk on its cash and cash equivalents.

Accounts receivable and revenue and support concentrations are comprised of the following private donors at December 31:

<u>Donor</u>	<u>2020</u>		<u>2019</u>	
	<u>Percentage of Accounts Receivable</u>	<u>Percentage of Total Revenue and Support</u>	<u>Percentage of Accounts Receivable</u>	<u>Percentage of Total Revenue and Support</u>
A	- %	14%	- %	20%
B	- %	- %	55%	16%
C	- %	- %	34%	- %
D	37%	- %	- %	16%
E	- %	16%	- %	13%
F	- %	11%	- %	- %
G	18%	- %	- %	- %
H	26%	- %	- %	- %

11. CONTINGENCY

In the ordinary course of NORD's business, NORD is from time-to-time involved in disputes concerning business and employment matters of NORD. While damages in connection with these disputes are possible, NORD denies any wrongdoing in these cases and is taking the appropriate legal steps in defense of these disputes. It is management's opinion that any potential settlement would not be material to the accompanying financial statements.

Beginning in March 2020, the COVID-19 pandemic in the United States has caused business disruption and a reduction in economic activity. While the disruption is expected to be temporary, there is uncertainty around the duration and the impact it will have on NORD's operations and financial position. Any financial impact to NORD, if any, cannot be reasonably estimated at this time.

12. UNEMPLOYMENT INSURANCE

NORD is self-insured for unemployment claims for two of their locations. NORD holds a prepaid account to fund the insurance through the Unemployment Services Trust. Claim liabilities are requested from the states through the Trust. As of December 31, 2020 and 2019, the balance in the prepaid unemployment insurance account was \$143,380 and \$124,579, respectively, which is included in prepaid expenses in the accompanying statements of financial position. The unemployment insurance account is available to fund future unemployment claims.

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Notes to Financial Statements
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13. LIQUIDITY AND AVAILABILITY OF FINANCIAL ASSETS

NORD regularly monitors liquidity required to meet its operating needs and other contractual commitments, while also striving to maximize the investment of its available funds. NORD has various sources of liquidity at its disposal, including cash and cash equivalents and a line of credit in the amount of \$750,000 (see Note 7).

For purposes of analyzing resources available to meet general expenditures over a twelve-month period, NORD considers all expenditures related to its ongoing activities of its mission as well as the conduct of services undertaken to support those activities to be general expenditures. In addition to financial assets available to meet general expenditures over the next twelve months, NORD anticipates collecting sufficient revenue to cover general expenditures not covered by donor-restricted resources.

As of December 31, 2020 and 2019, the total financial assets held by NORD that could readily be made available within one year of the statements of financial position date to meet general expenditures are as follows:

	<u>2020</u>	<u>2019</u>
Cash and cash equivalents	\$ 23,512,112	\$ 47,832,054
Accounts receivable, net	1,358,053	11,775,250
Investments	<u>25,613,110</u>	<u>-</u>
	50,483,275	59,607,304
Less - amounts with donor-imposed restrictions	<u>(41,438,384)</u>	<u>(53,125,003)</u>
Financial assets available to meet cash needs for general expenditures within one year	<u>\$ 9,044,891</u>	<u>\$ 6,482,301</u>

14. SUBSEQUENT EVENTS

On March 27, 2021, NORD's mortgage interest rate was modified from 4.9% to 3.5% (see Note 7).

On May 31, 2021, NORD's line of credit was extended through July 30, 2021 (see Note 7).